

Medical and family caregivers' conceptions in the face of advance directives

Concepções médicas e dos cuidadores familiares diante das diretivas antecipadas de vontade

Concepciones médicas y de los cuidadores familiares sobre las directivas anticipadas de voluntad

**Silvana Bastos Cogo^I, Marcio Rossato Badke^{II}, Luiza Carolina Santos Malheiros^{III}
Daiana de Araújo^{IV}, Aline Gomes Ilha^V**

Abstract: Objective: To understand how doctors and family caregivers understand the applicability of the Advance Directives to end-of-life care. **Method:** qualitative, descriptive and exploratory research, conducted with seven doctors of a university hospital in southern Brazil and seven family caregivers of patients at the end-of-life, from October to December 2014, from semi-structured interviews, submitted to discursive textual analysis. **Results:** two categories emerged: Advance Directives: the right to personal autonomy and conflicts and dilemmas in the applicability of Advance Directives. **Conclusion:** The Advance Directives are related to the respect of personal autonomy, professional support and reduction of the anguish and suffering of family care in view of the decision-making processes that involve the end of life. However, it is a practice surrounded by fears and concerns about its applicability and compliance by the professional.

Descriptors: Medicine; advance directives; terminally ill

Resumo: Objetivo: compreender como os médicos e cuidadores familiares entendem a aplicabilidade das Diretivas Antecipadas de Vontade no cuidado em final de vida. **Método:** pesquisa qualitativa, descritiva e exploratória, realizada com sete médicos de um hospital universitário do sul do Brasil e sete cuidadores familiares de pacientes em fase final de vida, no período de outubro a dezembro de 2014, a partir de entrevistas semiestruturadas, submetidas à análise textual discursiva. **Resultados:** emergiram duas categorias: Diretivas Antecipadas de Vontade: o direito à autonomia pessoal e conflitos e dilemas na aplicabilidade das Diretivas Antecipadas de Vontade. **Conclusão:** as Diretivas Antecipadas de Vontade estão relacionadas ao respeito da autonomia pessoal, respaldo profissional e redução das angústias e sofrimentos dos cuidados familiares diante dos

^I PhD in Nursing. Associate Professor of Department of Nursing at Federal University of Santa Maria (UFSM). Santa Maria, Rio Grande do Sul, Brazil. Email: silvanabastoscogo@gmail.com. ORCID: <http://orcid.org/0000-0002-1686-8459>

^{II} PhD in Sciences. Associate Professor of Department of Nursing at Federal University of Santa Maria (UFSM). Santa Maria, Rio Grande do Sul, Brazil. Email: marciobadke@gmail.com. ORCID: <http://orcid.org/0000-0002-9459-1715>

^{III} Undergraduate student in Nursing at Federal University of Santa Maria (UFSM). Santa Maria, Rio Grande do Sul, Brazil. Email: luizacsmalheiros@gmail.com. ORCID: <http://orcid.org/0000-0003-2005-2820>

^{IV} MSc student in Health Production at University of Santa Cruz do Sul (UNISC). Administrative technical nurse in education at Federal University of Santa Maria (UFSM). Santa Maria, Rio Grande do Sul, Brazil. Email: daianadearaujo@yahoo.com.br. ORCID: <http://orcid.org/0000-0003-4296-023X>

^V Undergraduate student in Nursing at Federal University of Santa Maria (UFSM). Santa Maria, Rio Grande do Sul, Brazil. Email: aline.gomes1996@hotmail.com. ORCID: <http://orcid.org/0000-0002-5715-9595>

processos decisórios que envolvem o fim de vida. Entretanto, constitui-se como uma prática cercada por medos e receios à sua aplicabilidade e ao cumprimento pelo profissional.

Descritores: Medicina; diretivas antecipadas; doente terminal

Resumen: Objetivo: comprender cómo los médicos y cuidadores familiares entienden la aplicabilidad de las Directivas Anticipadas de Voluntad en el cuidado al final de la vida. **Método:** investigación cualitativa, descriptiva, exploratoria realizada con siete médicos de un hospital universitario del sur de Brasil y siete cuidadores familiares de pacientes en fase final de la vida, entre octubre y diciembre de 2014, a partir de entrevistas semiestructuras, las cuales fueron sometidas a análisis textual discursiva. **Resultados:** se identificó dos categorías: Directivas Anticipadas de Voluntad: el derecho a la autonomía personal y conflictos; y dilemas en la aplicabilidad de las Directivas Anticipadas de Voluntad. **Conclusión:** las Directivas Anticipadas de Voluntad están relacionadas al respeto a la autonomía personal, a el respaldo profesional y a la reducción de las angustias y sufrimientos de los cuidados familiares delante de los procesos decisorios relacionados al fin de vida. Sin embargo, se constituye como una práctica rodeada por miedos y temores a su aplicabilidad y al cumplimiento por el profesional.

Descriptor: Medicina; Directivas anticipadas; Enfermo terminal

Introduction

The Advance Directives (AD), according to the Resolution No. 1995/2012, of the Federal Council of Medicine (CFM),¹ deals with set of wishes, previously and expressly expressed by the patient about care and treatments he wants or does not want to receive at the moment he is unable to freely and autonomously express his will.¹ In this context, the offer of a dignified death is a priority in the care of patients at the end of life, as the reduction of the suffering of the patient and family caregiver is fundamental in the decision making of the team.² It is noteworthy that the family caregiver is the one who assumes responsibility for care, thus, he/she provides daily care to the patient who has some dependence.³

Respect for patient autonomy is one of the markers of AD, impacting on the elimination of medical paternalism, when faced with the possibility of providing patients with adherence or not to treatments or procedures in the final period of life. Thus, AD are characterized as an instrument that enables the participation of individual in decisions about his health.⁴

However, it should be noted that Brazil lacks legislation that delimits the practice of AD, interfering with the compliance with the practice proposed by CFM.⁵ In the international

scenario, there is legislation on the practice of AD, as, for example, in the United States of America (USA), Spain, Portugal and Argentina, being accepted by the population, patients and health professionals.⁶⁻⁸ In the Brazilian scenario, there are contributions about AD, also described as vital will, involving theoretical analyzes of a philosophical and legal nature, and results of human research.⁹⁻¹⁸

The Brazilian State of São Paulo proposed to implement a single will register, a model that has been extended to other states in Brazil, such as Minas Gerais,¹⁹ aiming at the creation of a previous record of the patient's will, similar to those already existing in Spain and Portugal.

It is assumed that AD, in the context of hospital care, help to support and minimize the dilemmas and conflicts experienced by health professionals and family caregivers, in driving decisions that involve care and treatment in patients with progressive and advanced disease, with no prospect of cure, in addition to the prospective autonomy of the patient. Thus, this research was grounded in principled theory, especially the concept of autonomy regarding the right to self-government, privacy, individual choice and freedom from the will to be the engine of one's behavior.²⁰

In this sense, in order to promote reflection on end-of-life ethical issues, the aim was to contribute to studies on AD and precisely because there is still no legal regulation in Brazil and the lack of specifications on its applicability and effectiveness by doctors and family caregivers, it was delineated as a research question: what is the understanding of doctors and family caregivers about the applicability of AD to end-of-life patient? Thus, the work aimed to understand how doctors and family caregivers understood the applicability of AD to end-of-life patient.

Method

It was a descriptive and exploratory research, based on the qualitative approach. The scenario was a large university and public hospital in a city located in the geographic center of the state of Rio Grande do Sul (RS), which serves as a secondary and tertiary reference for the Midwest region, covering 46 municipalities serving exclusively the Unified Health System (SUS).

Seven resident doctors providing care for patients at the end-of-life in the institution and seven family caregivers of patients at the end-of-life in home-based care participated in the study. Thus, 14 participants were interviewed, considering a non-probabilistic intentional sample. The inclusion criteria for doctors were: to work in the medical clinic unit and in the home care service for at least six months. Regarding family caregivers, the criteria were: to be over 18 years old, provide care to the patient with a disease that no longer responds to curative treatment at home and family members designated as responsible for the patient. Exclusion criteria for participants were limited to the absence of doctors in the workplace during the period for data collection.

Data collection began after approaching doctors and family caregivers in order to meet them and inquire about their interest in participating in the research. Study participants were informed about the objectives and data collection strategy. After reading and signing the Informed Consent Form (ICF), the interviews were digitally recorded.

Data were produced through semi-structured interviews conducted individually in a single meeting. Interviews with doctors took place in the hospital environment, in private rooms and with family caregivers in their homes. The interview script included an introductory part related to the participants' biographical information and the following guiding questions were also used for health professionals and family members: respect for patient autonomy, knowledge and professional and family experiences regarding the applicability of AD and acting

in the presence of AD. The interviews were transcribed in full and the speeches were grammar corrected.

Data analysis took place through discursive textual analysis.²¹ The first stage of the analysis, which makes up the unitarization, required the detailed examination of the interview transcripts, fragmenting them to reach the constituent units related to the phenomenon, deconstructing the information.²¹ At the categorization stage, meaning units were grouped and progressively organized and named with greater precision. Finally, the capture stage of the new emergent happened through the intense impregnation of the analyzed materials, enabling the emergence of a renewed understanding about the applicability of AD, from the production of metatext from the analyzed corpus.²¹

The study obeyed the ethical precepts and obtained the approval of a Research Ethics Committee, under Opinion no. 168/2014. Data collection took place from October to December 2014, and the statements were identified by code (doctors: MED; family caregivers: FAM), followed by ordinal number, to ensure the confidentiality and anonymity of participants.

Results

Regarding the profile of the research participants, of the seven doctors, three were female and four male, with a mean age of 29 years old; the time of medical education ranged from nine to 30 years, and the average time of professional practice in the researched units of two years. With regard to family caregivers, of the seven respondents, ages ranged from 41 to 57 years old, with an average of 50 years old, and the length of care from two to three years. The family caregiver's relationship was three husbands and two wives; a daughter and a niece. Regarding education, two reported having incomplete high school; two attended incomplete elementary school; one a complete high school; one with a technical background and one interviewed with a higher education on going.

It is noteworthy that the research participants were unaware of the AD, as well as their applicability in the Brazilian context, requiring, in order to carry out the interviews, the prior explanation to those who were unaware of the concept, based on CFM Resolution 1995/2012.¹ It is noteworthy that the availability of the concept provided the research participants with the possibility of constructing thought from the perspective of applicability of the Advance Directives, in line with the idea of renewed comprehension subsidized by textual and discursive analysis. Thus, from the collected data, it was possible to group the conceptions of doctors and family caregivers regarding the practice of AD, in two categories: Advance Directives: the right to personal autonomy and conflicts and dilemmas in the applicability of Advance Directives.

Advance Directives: The Right to Personal Autonomy

AD reflect on the idea of supporting the actions of health professionals, supporting family caregivers in decisions that involve therapeutic adjustments and, especially, patients who may have their wills and wishes respected. It is important to highlight that AD enable, when properly employed, just that, that is, the right to have their beliefs, aspirations and deliberations fulfilled and respected.

[...] autonomy is the ability to decide and autonomy we respect [...] certainly for terminal patients we take autonomy, when we ask the conducts.
(MED.2)

[...] I intend to accept her decision. If she can make it manifest, we will have more protection [...] for sure, not only for me, but for her as well.
(FAM.6)

Based on the above, there is the recognition by doctors and family caregivers of the right to personal autonomy. On the other hand, there is a fear of legal repercussions and judicial problems regarding the compliance with AD, which affect its applicability by doctors. In addition, there is the fear of family caregivers about the change of opinion, that is, the idea that

the person has decided for something that has been or is manifested and that, perhaps, does not correspond to the real wishes of those who are at the end of life.

[...] If it was very explicit and we as doctors, health professionals more legally supported, because nowadays there is much this issue of the process, would be much more interesting. And I think that the autonomy of the patient has to be respected [...] if you are putting the life of a third party at risk, surely the doctor will have to intervene, especially at the end of life. I think it is important to respect patient autonomy. (MED.3)

[...] I always want to respect her will, but I am a little worried, because today she does not want to, but when the time comes and she has signed (the advance directives), as in case she cannot resolve and want that they do. [...] signing when the person has the problem is one thing and he/she knows what will happen, but when it is happening it can be another. (FAM.6)

As illustrated by the research participants, the idea of considering personal autonomy is the triggering factor when considering the possibility of respecting the expressed wishes. Thus, the focus is on the fact that when it is recognized that the patient has a progressive and advanced disease, there is a need to be able to put their wishes on the agenda, so that with his/her deterioration and impairment of autonomy, there is no prejudice to the decisions, so that, thus, the expressed wishes are fulfilled by professionals and family members.

[...] as your independence is being compromised, the commitment to autonomy begins, you already have to worry and talk to the person. Patient X's example has the cognitive fully preserved, so you have to talk now; now is the time to respect whatever she wants. (MED.4)

Another aspect refers to the fact that, although it should be considered that AD can improve personal autonomy, there are doubts about the preparation of health professionals and/or family caregivers to introduce the subject of AD to patients, besides the difficulty in enabling that the idea of death is on the agenda.

[...] if they had the AD would greatly improve the issue of autonomy. Only I don't know if they are prepared to think about death and that kind of

thing. Suddenly it would have to take a lot of work to be able to do the AD, because it must be complicated to define for the patient himself. (MED.5)

[...] suddenly in a conversation, maybe one day talking, I'll ask her about these questions. [...] because it is something we never think to ask, but it is super important. (FAM.5)

From the point of view of AD, so that they are cultivated ensuring the principle of autonomy, unanimously listed by the research participants, there are fragile points that still make it impossible and/or difficult to apply it, especially related to the lack of practice and the conducts for its application.

Conflicts and dilemmas in the applicability of Advance Directives

One of the dilemmas is to fulfill a wish exposed in AD when the patient arrives at the hospital for the emergency room and how to consider restricting treatment when there is insufficiently clear information about the conditions of the disease. In addition, the family members responsible for these patients may feel afraid and do not want to fulfill the wishes previously expressed.

[...] in an emergency situation and depending on the backing is a bit complicated. In our midst now, suddenly, you can assert the will of one or the other, it becomes complicated in an emergency, such as behaving yourself. The ideal is to have the time and knowledge to organize things in the best way. (MED 2)

[...] if he had left it written (AD), honestly, I don't know if I would let him die, because I don't know if I would have that right, I wanted him to stay with me as long as possible. (FAM.2)

These speeches about this aspect are that they give rise to a conflict, a discussion and reflection about the conduct and decisions related to end-of-life care, when the family contradicts the decision expressed by the patient and the best alternative listed by the doctors.

[...] If the patient says he does not want chemotherapy, there's nothing to do. No one will oblige, but the bad thing is that in reality the family must accept it too. From the moment the patient becomes unable and the family says no, you will have to invest! We have to invest, because there is the issue of the process. (MED.3)

It is noteworthy that, sometimes, family members' manifestations may be related to uncertainties caused by the difficulty in communication among health professionals, family members and patients, as well as misdiagnosis and omission of information about the disease's condition and impairment to family members and patients.

[...] the doctor who performed the surgery, she didn't give me explanations and I asked her to explain better what was happening. She wouldn't let us talk, ask our questions. I think in that part she could have given a bigger question. (FAM.1)

[...] this issue of diagnosis was always very confusing [...]. I asked one of the doctors I believed because each one said one thing and the other said another. (FAM.2)

In this speech, the family expressed dissatisfaction with the uncertainties of the diagnosis and the difficulty in communicating with doctors, which can indeed be seen from the statements of medical participants when they expressed that they were unprepared to deal with the idea of a patient's death, as well as the difficulty they found in communicating about the condition of a patient who was at the end-of-life.

[...] we have difficulty dealing with terminal patients. [...] The feeling is of powerlessness, that is the feeling. (MED.1)

[...] the most difficult situations are the acceptance of their terminal condition, that we can say that the patient will not leave this, that he will not improve [...] that we no longer have what to do (in terms of treatment). (MED.5)

Also, from the considerations made by the participants, the university academies that could propose practices, supporting the issues related to end-of-life care and AD.

[...] In Brazil we need a few years to learn how to use the document (AD, and learn how to do it too. Not today, but I know it would have the ability to be implemented [...] massive training could be done with the professionals [...] In the end it turns out that the preparation is little.
(MED.2)

Discussion

AD correspond to a new concept to be disseminated and implemented in the Brazilian context, as they include aspects related to the possibility of the wills, beliefs and wishes of patients at the end-of-life. These should be respected by those who face situations of uncertainty regarding the conduct to be conducted in treatment and care, when there is no prospect of cure, such as the situation of family caregivers and health professionals, especially doctors.

Given this, it was found that there is the right to guarantee the patient's personal autonomy, from the applicability of AD, and this should be evident from the perspective of doctors and family caregivers. In this respect, it is confirmed that AD enable the exercise of the fundamental right to liberty, since it is a space that the individual has to make personal decisions, immune to external interference, whether from doctors, family or anyone and/or institution will to impose its own will.¹¹ Thus, manifestations of autonomous decisions preceding periods of inability should be considered valid and binding after becoming unable. Respecting the autonomous patient is, at the very least, recognizing their right to have their opinions, make their choices and act on their personal values and beliefs.²⁰

AD still aim to ensure the right of the patient to die with dignity, according to their personal conceptions.⁵ It is also added that AD is based on the principles of autonomy, respect for people and loyalty, bringing as benefits, the improvement of the doctor-patient relationship and patient self-esteem.¹¹

In this perspective and emphasizing the findings of this research, the question arises that medical professionals admittedly valued the idea of compliance with AD, as an alternative to maintaining human dignity and personal autonomy, and Resolution no. 1,995/121 represents an advance in discussions about AD in Brazil.¹² However, doctors fear this practice as to its legality, to the extent that there is no Brazilian law to support its practice. In this sense, it is this demand that is in the agenda because, in fact, the problem of legal limits refers to the concern with the legality of submission to the Resolution and the risks inherent to possible legal questions regarding the conduct of nonintervention by doctors.¹⁰

It should be noted that it is necessary to consider that the Resolution does not exhaust the subject, but demonstrates and corroborates with the interviewed professionals the need for specific legislation on AD in order to regulate it. However, the use of AD will be of no use unless there is a collective effort to ensure that the will expressed in them is fulfilled. The truth is that it is not enough to guarantee the right of the individual to express his will, but it must also be assured that it will be fulfilled.¹⁴

Family caregivers report in their statements, anguish, fears and concerns about the possibility of compliance with the AD, considering the idea of patient's change of opinion due to the prior completion of the AD. In this sense, in the Netherlands, from a survey of patients in good, moderate and poor health, all with prior AD, it was found that their perceptions of dignity and wishes remained stable during the course of the disease, suggesting that the wishes expressed in advance and their understanding of dignity had not substantially changed with changes in health.²²

However, in the context of AD, people's beliefs, choices and consent may change over time, and moral and interpretative problems emerge, as it would be inconsistent to impose a will on another action determined by an advance directive. Thus, care must be taken in judging

the patient's ability by distinguishing the autonomous decisions that must be respected from those decisions that need to be checked and perhaps supplanted by a substitute.²⁰

Some interviews showed that family caregivers did not respect and sometimes disregarded the wishes previously expressed by patients. Given this situation, the doctors interviewed stated that they could resist the fulfillment of the wills of patients with an AD, due to the contradiction of family caregivers. Thus, this study corroborated a study conducted in Brazil in which doctors had difficulties in respecting the patient's will, even if written, when the family was contrary to this will.¹⁴

From this perspective, the patient's prior choice should be honored, since doing something against the patient's express will is a violation of his autonomy, disrespect, and insult to the person, that is, treating him as a means, according to with the goals of others, without worrying about what this individual want. In this sense, interventions against early directives infringe the principle of respect for autonomy although they may in some cases be justified, as there may be problems of interpretation and determination of whether the agent was able when formulating AD.²⁰

In this light, considering the findings of this research related to the difficulty of the interviewed medical professionals to discuss the issue of terminality and the elaboration of an AD, communication between doctors, patients and family members was found to have failed in the health service, and even more so when communication was difficult news. Thus, effective communication between all involved is a therapeutic measure that provides the patient and family with harmonious and peculiar care. This prevents family members from deciding contrary to the patient's will.²³

Also, there is the fact that autonomous action does not require full understanding or lack of influence because, in general, decisions are influenced by personal wishes, family pressures, legal obligations and institutional pressures. Autonomy is related to the ability to rationally

accept, identify with or repudiate a wish or preference, from the understanding of the transmitted information that makes it possible to make a judgment, aiming at a decision that allows the free manifestation of a wish. Therefore, the need to pay attention to the way information is presented, which can manipulate the patient's perception and reaction, resulting in an unsatisfactory basis for their decision making.²⁰ In this sense, the research findings, especially of doctors, brought the need to provide patients with the possibility of knowing their diagnosis to make their decisions and express their wishes.

It can be said, then, that AD represents an advance towards respect for personal autonomy, however, for the practice of writing to be opportunized, it is necessary that those involved are aware of the diagnoses and that communication is efficiently translatable, in order to enable its clarification. In this perspective, this research pointed out that family caregivers had difficulty communicating about their family members' understanding of the disease. Therefore, it is essential to be aware of the diagnosis, treatment options and prognosis, in order to preserve the dignity of the patient, appropriating him/her the right to make decisions jointly with the family and the health team, regarding treatment, as in relation to place of residence until end of life.²⁴

Patients who can talk to their doctors about end-of-life may have greater mastery of their own illness and terminality, thereby ensuring their autonomy and having a greater chance of dying in peace and dignity. With this, family members also better elaborate the grieving process. Therefore, death is still an uncomfortable subject, perhaps a taboo, even for people in general and for most health professionals. People do not talk to their family members about how they would like to be treated if they had a serious and irreversible illness or about their own death. Thus, they are subject to interventions that do not match their wishes. However, reflecting on the possibility of finding oneself in an end-of-life situation is not an easy task,

since even if one refers to the idea of presenting oneself in a terminal situation, such situation does not guarantee the decisions that would be made to experience it.²⁵

In this sense, AD can promote discussion of a frequent problem involving the care and treatment provided to end-of-life patients, which, on several occasions, make it impossible for family caregivers responsible for patients and health professionals, especially doctors, to make difficult, dilemmatic and conflicting decisions from the point of view of ethics and bioethics. Conflicts and dilemmas in the application of AD can be circumvented with carefully worded documents, appropriate counseling, and expert explanations of medical possibilities and treatment options. However, some interpretation problems will remain despite the greater involvement of doctors and the education tools used.

It is noteworthy, by the results of this research, the emergence of aspects related to disability in the preparation of medical professionals to care for patients and family members with a disease with no prospect of cure. Thus, there is no possibility of implementation and effectiveness of the practice of AD and, consequently, to enforce the wills and wishes of unable patients, if there is no precise guidance to those involved in the process, such as family members and patients are aware that can build their AD.

Regarding the analysis of the statements of the doctors and family caregivers participating in the research, it could be highlighted that the AD is an instrument able to assist in the maintenance of human dignity, by guaranteeing the fulfillment of their wishes, that is, respect for personal autonomy. However, in the national reality, it is necessary educational advances and debates regarding the knowledge, applicability and compliance of AD, so that, effectively, humanization in terminal care can ensure the patient, at the end-of-life, the maintenance of his dignity and the right that his wishes are fulfilled and his personal autonomy maintained.

Conclusion

Patient autonomy is a right that health professionals should consider in the context of health care. AD appear in the Brazilian scenario as a viable alternative to support in conducts, facing end-of-life situations, such as those related to the limitations of therapeutic efforts. However, the applicability of AD is far from ending the controversies that permeate this issue related to its application; the expectation that the will of the people corresponds to the final decision; the insertion of the health professional in the process of AD and if he/she can or is able to change the patient's decision, besides other doubts.

The reality experienced by doctors and family caregivers, facing the care of patients at the end-of-life and the imagination about AD, is linked to guaranteeing the patient's personal autonomy. However, what is exposed is a challenging reality, as to guarantee the wills and wishes previously expressed by the fact that there is uncertainty about the judicial repercussions; by the patient's change of opinion, without time to express it and by the difficulties rooted in society in talking about aspects that involve the end of life and death. In addition, there are the dilemmas and conflicts arising from the possibility of applying AD, related to compliance by doctors and compliance with family members, the uncertainties of diagnoses, and communication deficiencies among patient-family-doctor.

It is noteworthy that this practice is in force in Brazil, and there are signs of adopting strategies to expand the dissemination of AD among health professionals and society as well as focus, in academic spaces, discussions on terminality, ethics and bioethics. The idea is to propose actions in which society knows about AD, such as fostering support to patients, family members and health professionals, who face dilemmatic and conflicting situations in decisions that involve end-of-life care. These actions may qualify patients' co-participation in decisions related to their life and death.

The limitations of this study were framed by the restriction of the number of research participants and the delimitation of the study place, that is, it was performed in two units of a hospital in the central region of Rio Grande do Sul, whose experiences of doctors and family caregivers may differ in other places and hospital environments. In addition, another limitation referred to the need to make the previous explanation to respondents who were unaware of the concept of AD, in order to support the construction of thinking from the perspective of applicability of the Advance Directives.

On the other hand, it is considered that the results obtained gave depth to the understanding that AD is an alternative to provide personal autonomy, based on the fulfillment of their wills, despite the limitations and conflicts that hinder its implementation in the hospital context.

Referências

1. Conselho Federal de Medicina (BR). Resolução n. 1995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes [Internet]. 2012 [acesso em 2017 set 12]. Disponível em: http://www.portalmedico.org.br/resolucoes/CFM/2012/1995_2012.pdf
2. Santos FPPG, Comassetto I, Porciúncula AIC, Santos RM, Ferreira FAS, Magalhães APN. Ortotanásia e distanásia: percepção dos profissionais de saúde de uma Unidade de Terapia Intensiva. *Ciênc Cuid Saúde* [Internet]. 2016 [acesso em 2018 jul 05];15(2):288-96. Disponível em: <http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/26017>
3. Faria EBA, Scardoelli MGC, Castro VC, Nishida FS. Vivências de cuidadores familiares de pessoas idosas com doença de Alzheimer. *Ciênc Cuid Saúde* [Internet]. 2017 [acesso em 2019 mar 06];16(1):1-7. Disponível em: <http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/31004>. doi: <http://dx.doi.org/10.4025/cienc cuidsaude.v16i1.31004>
4. Moreira MADM, Costa SFG, Cunha MLDM, Zaccara AAL, Negro-Dellacqua M, Dutra F. Testamento vital na prática médica: compreensão dos profissionais. *Rev Bioét (Impr)* [Internet]. 2017 abr [acesso em 2018 abr 08];25(1):168-78. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S198380422017000100168&lng=en&nrm=iso doi: <http://dx.doi.org/10.1590/1983-80422017251178>.

5. Dadalto L. Diretivas antecipadas de vontade: ensaios sobre o direito à autodeterminação. Belo Horizonte: Letramento; 2013. Capacidade versus discernimento: quem pode fazer diretivas antecipadas de vontade? p. 228-9.
6. Evans N, Pasma HR, Alonso TV, Van den Block L, Miccinesi G, Van Casteren V, et al. End-of-life decisions: a cross-national study of treatment preference discussions and surrogate decision-maker appointments. PLoS One [Internet]. 2013 [acesso em 2017 set 12];8(3): e57965. Disponível em: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0057965>
7. Keam B, Yun YH, Heo DS, Park BW, Cho CH, Kim S, et al. The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. Support Care Cancer [Internet]. 2013 [acesso em 2017 set 12];21(5): 1437-44. Disponível em: <http://link.springer.com/article/10.1007/s00520-012-1689-z#page-1>
8. Cucalón-Arenal JM, Marín-Ibáñez A, Cía-Gómez P, Blay-Cortés MG. Opinión de los universitarios sobre los cuidados al final de la vida. FEM [Internet]. 2013 [acesso em 2017 set 12];16(3):181-6. Disponível em: <http://scielo.isciii.es/pdf/fem/v16n3/original7.pdf>
9. Alves CA. Linguagem, diretivas antecipadas de vontade e testamento vital: uma interface nacional e internacional. Bioethikos [Internet]. 2013 [acesso em 2017 set13];7(3):259-70. Disponível em: <https://saocamilo-sp.br/assets/artigo/bioethikos/105/1810.pdf>
10. Bussinguer ECA, Barcellos IA. O direito de viver a própria morte e sua constitucionalidade. Ciênc Saúde Colet [Internet]. 2013 [acesso em 2017 ago 24];18(9):2691-8. Disponível em: https://www.scielo.org/article/ssm/content/raw/?resource_ssm_path=/media/assets/csc/v18n9/v18n9a24.pdf
11. Dadalto L. Distorções acerca do testamento vital no Brasil (ou o porquê é necessário falar sobre uma declaração prévia de vontade do paciente terminal). Rev Bioet Derecho [Internet]. 2013 [acesso em 2017 jun 05];28:61-71. Disponível em: <http://scielo.isciii.es/pdf/bioetica/n28/articulo5.pdf>
12. Dadalto L. Reflexos jurídicos da Resolução CFM 1995/12. Rev Bioét (Impr) [Internet]. 2013 [acesso em 2017 jun 05];21(1):106-1. Disponível em: <http://www.scielo.br/pdf/bioet/v21n1/a12v21n1>
13. Rocha AR, Buonicore GP, Silva AC, Pithan LH, Feijó AGS. Declaração prévia de vontade do paciente terminal: reflexão bioética. Rev Bioét (Impr) [Internet]. 2013 [acesso em 2018 jan 03];21(1):84-95. Disponível em: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/790
14. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. Rev Bioét (Impr) [Internet]. 2013 [acesso em 2017 set 12];21(3):463-76. Disponível em: <http://www.scielo.br/pdf/bioet/v21n3/a11v21n3.pdf>

15. Cassol PB, Quintana AM, Velho MTAC. Diretiva antecipada de vontade: percepção de uma equipe de enfermagem da hemato-oncologia. *J Nurs Health* [Internet]. 2015 [acesso em 2017 nov 09];5(1):04-13. Disponível em: <https://periodicos.ufpel.edu.br/ojs2/index.php/enfermagem/article/view/5497>
16. Chehuen Neto JA, Ferreira RE, Silva NCS, Delgado AHA, Tabet CG, Almeida GG, et al. Testamento vital: o que pensam profissionais de saúde? *Rev Bioét (Impr)* [Internet]. 2015 [acesso 2017 dez 17];23(3):572-82. Disponível em: <http://www.scielo.br/pdf/bioet/v23n3/1983-8034-bioet-23-3-0572.pdf>
17. Silva JAC, Souza LEA, Costa JLF, Miranda HC. Conhecimento de estudantes de medicina sobre o testamento vital. *Rev Bioét (Impr)* [Internet]. 2015 [acesso em 2017 dez 17];23(3):563-71. Disponível em: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/1102
18. Cogo SB, Lunardi VL, Quintana AM, Girardon-Perlini NMO, Silveira RS. Desafios da implementação das diretivas antecipadas de vontade à prática hospitalar. *Rev Bras Enferm* [Internet]. 2016 [acesso em 2017 set 12];69(6):1031-8. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672016000601031&lng=en
19. Dadalto, L. Aspectos registrais das diretivas antecipadas de vontade. *Civilistica.com* [Internet]. 2013 [acesso em 2018 fev 24];2(4):1-8. Disponível em: <http://civilistica.com/aspectos-registrais-das-diretivas-antecipadas-de-vontade/>
20. Beauchamp TL, Childress JF. *Princípios da ética biomédica*. 4ª ed. São Paulo: Loyola; 2002.
21. Moraes R, Galiazzi MC. *Análise textual discursiva*. 2ª ed. Rev Ijuí: Ed. Unijuí; 2013.
22. Albers G, Pasman HR, Deliens L, de Vet HC, Onwuteaka-Philipsen BD. Does health status affect perceptions of factors influencing dignity at the end of life? *J Pain Symptom Manage* [Internet]. 2013 [acesso em 2018 jan 21];45(6):1030-8. Disponível em: <https://www.ncbi.nlm.nih.gov/pubmed/23141880>
23. Bastos BR, Fonseca ACG, Pereira AKS, Silva LCS. Formação dos profissionais de saúde na comunicação de más notícias em cuidados paliativos oncológicos. *Rev Bras Cancerol* [Internet]. 2016 [acesso em 2017 dez 17];62(3):263-6. Disponível em: http://www1.inca.gov.br/rbc/n_62/v03/pdf/10-artigo-opiniao-formacao-dos-profissionais-de-saude-na-comunicacao-de-mas-noticias-em-cuidados-paliativos-oncologicos.pdf
24. Kovács MJ. Cuidando do cuidador profissional: o sofrimento da equipe de saúde no contexto hospitalar. In: Pessini L, Bertachini L, Barchifontaine CP, organizadores. *Bioética, cuidado e humanização*. São Paulo: Loyola; 2014. (Sobre o cuidado respeitoso; vol. 2).
25. Cogo SB, Lunardi VL, Quintana AM, Girardon-Perlini NMO, Silveira RS. Diretivas antecipadas: desejos dos profissionais da saúde e cuidadores familiares. *Rev Baiana Enferm* [Internet]. 2017 [acesso em 2018 jul 05];31(1):1-12. Disponível em: <https://portalseer.ufba.br/index.php/enfermagem/article/view/16932/pdf>

Corresponding author

Silvana Bastos Cogo

Email: silvanabastoscogo@gmail.com

Address: Av. Roraima nº 1000 - Prédio 26, sala 1339.

CEP: 97105900

Author Contributions

1 - Silvana Bastos Cogo -

Research project design and planning, data collection and analysis, writing and critical review.

2 - Marcio Rossato Badke

Writing and critical review.

3 - Luiza Carolina Santos Malheiros

Writing and critical review.

4 - Daiana de Araújo

Writing and critical review.

5 - Aline Gomes Ilha

Writing and critical review.

How to cite this article

Cogo sb, Badke mr, Malheiros LCS, Araújo D, Ilha AG. Concepções médicas e dos cuidadores familiares diante das diretivas antecipadas de vontade. Rev. Enferm. UFSM. 2019 [Acesso em: Anos Mês Dia];vol e2: P1-P20. DOI:<https://doi.org/10.5902/2179769233083>